

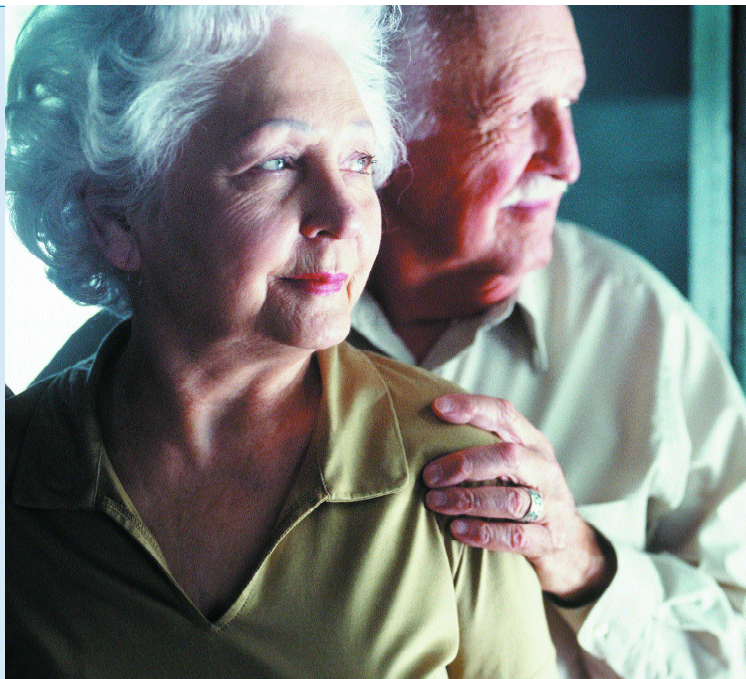
# Family Caregiving In Utah

*A Resource Guide for Family Caregivers*



UTAH COALITION FOR CAREGIVER SUPPORT  
COMPLETING THE CARE





## *Are you a caregiver?*

**If you do any of the following for another individual you are probably a caregiver**

- Provide direct financial support
- Manage their personal finances
- Do household chores for a person, such as shopping, cooking, laundry, and/or maintenance of living quarters
- Assist with personal care (dressing, bathing, feeding, toileting)
- Provide assistance moving about in the living quarters
- Provide transportation
- Administer medications
- Provide companionship by personal visits or telephone
- Make or receive their telephone calls
- Arrange/coordinate outside help

If you said yes to any of these questions you are a caregiver, but you're not alone. **Nationwide, one of every four persons is providing care for a relative or friend age 50 or older.** You're part of a very important and diverse group. Caregivers can live with their relative or can provide long-distance caregiving. Some caregivers are employed while others are juggling the care of a parent as well as that of children. Caregiving demands time, resources, love, and energy. While there is currently no 'one-stop shop' to get all of your questions answered, you are not alone as you journey through this life passage. Your local Area Agency on Aging (AAA) is an important place to begin.

Utah's network of caregiving service providers have designed this booklet to help you navigate the caregiving maze. We hope it helps you to:

- Learn about basic caregiving resources
- Identify your local resource team
- Develop a caregiving plan

# Utah Coalition for Caregiver Support (UCCS)

## Vision and Mission Statement

**Vision:** Utah caregivers will have knowledge of and access to resources that support them.

**Mission:** UCCS creates awareness of caregiving issues and improves the quality of life for caregivers/care receivers through:

- Advocacy
- Information
- Support and access to resources

## Utah Caregiver Support History

While Utah has recognized the importance of family care and has offered services to benefit caregivers for a number of years, nationally there was no comprehensive program to assist family caregivers. The National Family Caregiver Support Act, a part of the Older Americans Act, now helps fill this gap. This act authorized a variety of services to support the important work of family caregivers.

Through this federal legislation, Utah has embarked on a new effort to assist family members and friends in their caregiving roles. The Utah Caregiver Support Program strives to complement the efforts of family caregivers by providing information, supports and services. Utah’s Caregiver Support Program is administered by the Department of Human Services, Division of Aging and Adult Services, with direct services provided through the Area Agencies on Aging (AAA) and community partners.

Through the Utah Caregiver Support Program, public and private organizations statewide are partnering to provide information and services to family caregivers and to educate and train the professionals who work with them. These groups have formed local partnerships that make up the Utah Coalition for Caregiver Support.



## Area Agencies on Aging (AAAs)

Area Agencies on Aging provide a link to in-home services, or services that provide temporary relief for persons caring for an individual who is ill, injured or frail (also known as respite services). These services can be provided at home, in an adult day care center or other setting.

Other services include:

- home-delivered meals
- congregate meals
- adult day programs
- care management
- in-home aide service
- information and assistance
- senior center programs
- transportation
- health promotion
- housing and home-improvement
- medication management
- abuse, neglect or exploitation education and awareness

The availability of these services varies in each county. Contact the Utah Caregiver Support Program at your local Area Agency on Aging, or visit the Division of Aging and Adult Services' online directory of local services at [www.hsdaas.utah.gov](http://www.hsdaas.utah.gov)

## Support Groups

Support groups can be found across the state. Many are designed for caregivers of people with specific diseases and are often sponsored by national associations like the Alzheimer's Association and the American Parkinson Disease Association. (See Resources page for more information.)

There are also general caregiver support groups. Many groups are sponsored by local aging service providers and community organizations. A growing number of support groups are offered online as an option for caregivers with Internet access that have limited ability to attend group meetings.



**Support groups allow caregivers to:**

- discuss their concerns and common experiences
- receive and offer emotional encouragement
- share practical solutions to caregiving situations

## Training / Workshops

A variety of workshops and training resources are available to assist caregivers in carrying out their role. The workshops may include:

- Self-care techniques for caregiver
- Medication and care management
- Information and resources
- Safety in the home
- Managing difficult behaviors
- Transfer and fall prevention techniques

For information, contact your local Area Agency on Aging, the Utah Caregiver Support Program at (801) 538-3910 or visit the Utah Coalition for Caregiver Support website at [www.caregivers.utah.gov](http://www.caregivers.utah.gov).



Use the following chart to help develop a caregiving plan:

My relative	What they need	Where they can get it
...really needs to get out and socialize	Socialization / Volunteering – Programs	Senior centers, adult day care, friendly visitors, city recreation department, Faith in Action, the Utah Commission on Volunteers.
...is grieving over the death of a loved one	Bereavement Support – Dealing with the normal grieving process.	Bereavement support programs, hospice programs, hospitals, local funeral homes.
...cannot drive or use public transportation and taxicabs are too expensive	Transportation for older persons	AAAs, private transportation, people with disabilities transportation.
...is unable to remain in his / her present housing	Special housing options are available for the elderly	Local housing authority, local AAAs, geriatric care managers.
...needs help with food preparation and/or house-keeping and/or laundry	Homemaker Services – Non-medical service to help an older person remain in the home.	Private homemakers, personal care agencies, local AAAs.
...needs help with personal care (bathing, dressing, grooming, toileting)	Home Health or Personal Care Aide – Personal and basic health care provided by a specialist.	Home health agencies, public health nurses, personal care agencies, geriatric care managers.
...needs skilled nursing, occupational, speech or physical therapy	Skilled nurse or therapist	Home health agencies, public health nurses, geriatric care mangers.
...really needs 24-hour supervision even though he/she fights it	Private Home Care, Nursing Home Care– 24-hour medical supervision.	Personal care agencies, home health agencies, local AAAs, geriatric care managers.
...cannot be left alone during the day	Monitoring/Safety-Volunteers who visit with the elderly or a facility which provides constant supervision	Adult day care, live-in attendant, local AAAs, home health agencies, geriatric care managers.
...has health care costs which are overwhelming	Reducing cost of quality health care.	Medicare, Medicaid, local AAAs.
...is depressed / suspicious / angry all the time, just sits	Talk with primary care physician. A mental health evaluation may be necessary to assess psychological stability.	Mental Health Departments, geriatric care managers, psychiatric hospitals, emergency room.
...has a terminal illness and wants to die at home	Hospice – Medical and social services designed for terminally ill patients.	Utah Hospice Organization, Cancer Society, church or synagogue

Legal Services

Many older people experience problems that threaten their autonomy, dignity, health, income, rights, and security. Many of these problems can be avoided or remedied by legal intervention. (See Resources on page 7)

Advance Directives

Advance care planning is deciding about the kind of health care you want at the end of life. Advance health care directives are the legal documents in which you give written instructions about your health care, in the event you cannot speak for yourself.

End-of-Life Care Partnership of Utah provides a step-by-step guide to advance care planning. The workbook, *Tool Kit for Health Care Advance Planning*, is designed to help individuals and families plan for the care they want at the end of life. The workbook is available through the End-of-Life Partnership. (See Resources on page 7)

Health Insurance Information

Medicare:

Most adults age 65 and older and certain disabled adults receive Medicare health insurance. Medicare only covers a portion of costs such as hospitalizations, doctors' visits, and diagnostic testing. In some cases, it may cover short-term care in a skilled nursing facility

and limited home health care. Medicare-approved home health care may include the services of a nurse, physical therapist, speech therapist, medical social worker, occupational therapist and home health aide. Medicare is the national health insurance program for people age 65 and older and for some younger persons with disabilities.

Medicare is divided into four parts:

- Hospital Insurance (Part A)
- Medical Insurance (Part B)
- Medicare + Choice (Part C)
- Drug Benefit (Part D effective 2006)

Medicare, Part A

helps pay for care in a hospital or nursing home, limited home health services, and hospital care. There are usually no premiums to pay for Medicare Part A, but there is an annual deductible and a co-insurance payment.

Medicare, Part B

helps pay for doctors' services, outpatient hospital care, and other medical services that Part A doesn't cover.

**Long-Term Care**– Many people think that Medicare provides long-term care. The reality is that there is no long-term, non-medical care coverage under Medicare. Medicare does provide limited short-term care after a hospital stay, and home health care services only under certain conditions. Coverage is not available for long-term chronic care.





**Hospice** – Medicare provides a hospice benefit for persons with a terminal diagnosis and a prognosis of six months or less. The Hospice interdisciplinary team includes the patient’s physician, nurses, home health aides, a spiritual and bereavement counselors, medical social services, physical, occupational and speech therapists, and volunteers. In addition, hospice care includes medications, medical equipment and supplies, counseling and short term respite for caregivers, and general inpatient care for pain and symptom control. For information on hospice services, call AAA, visit [www.medicare.gov](http://www.medicare.gov) or The Utah Hospice & Palliative Care Organization at (801) 582-2245 or (888) 325-4150.

*Medicare+Choice, Part C*  
allows for options in the delivery of Medicare covered services. Services are delivered through a Health Maintenance Organization (HMO) or private fee for service.

*Drug Benefit, Part D (effective January, 2006)*  
allows for a Medicare drug program. Federal rules for this program are pending.

**Medicaid:**  
A program that provides health care insurance for low-income older (age 65+) and disabled adults. It also covers nursing home care for eligible individuals. Contact your Department of Workforce Services for eligibility information. For information call 800-662-9651.

Other Helpful Resources

Since Medicare does not cover all health care costs, most Medicare beneficiaries have additional private coverage either through their former employers or with a Medicare Supplement policy. Additional long-term care insurance can be purchased to cover some of the costs of home care and nursing facility care. There are limits on both of these types of insurance as well as state laws to protect the consumer. For insurance counseling and assistance, call the Health Insurance Information Program (HIIP) (see Resource Information) or the Department of Insurance at [www.insurance.utah.gov](http://www.insurance.utah.gov).

**Federal Tax Benefits**  
You may be able to claim a tax credit if you pay someone to care for your spouse or dependent who is not able to care for him/herself. The credit can be up to 30% of your expenses. For further information, contact the Internal Revenue Service online at [www.irs.gov](http://www.irs.gov).

**Assistance in Filing Tax Benefits**  
AARP-Tax-Aide and Volunteer Income Tax Assistance (VITA) programs offer free assistance in preparing tax returns. For information contact AARP Tax-Aide at (888) 227-7669, or see the website: [www.aarp.org/taxaide](http://www.aarp.org/taxaide). For VITA call (800) 829-1040 or see the website: [www.irs.gov](http://www.irs.gov).

**Family and Medical Leave**  
Under the Family and Medical Leave Act (FMLA) of 1993, employees meeting eligibility requirements can take up to 12 weeks of unpaid, job-protected leave in a 12-month period to care for an ill family member. Check with your employer for eligibility questions, or visit the website [www.dol.gov/elaws/fmla.htm](http://www.dol.gov/elaws/fmla.htm).



**AARP Utah, 866-448-3616**

A membership organization for people 50 and over that provides information, education and advocacy on legislative, consumer and legal issues.

**Visit:** [www.aarp.org/life](http://www.aarp.org/life)

**Adult Protective Services, 800-371-7897**

Investigators are located throughout the state and work with agencies and family members to stop abuse, neglect and exploitation of older adults. Any person who has reason to suspect such abuse is mandated by law to report their concerns.

**Alzheimer's Association, Utah Chapter  
800-371-6694**

Provides education and support for people diagnosed with Alzheimer's disease and other dementia, and to their families and caregivers.

**Visit:** [www.alzutah.org](http://www.alzutah.org)

**American Cancer Society  
800-234-0533, (801) 483-1500**

Dedicated to eliminating and preventing cancer through research, education, advocacy and service.

**Visit:** [www.cancer.org](http://www.cancer.org)

**American Parkinson Disease Association,  
801-585-2354**

Provides education and support for people with Parkinson's disease.

**Visit:** [www.apdaparkinson.com](http://www.apdaparkinson.com)

**The Arc of Utah, 800-371-5060, 801-364-5060**

Advocates for and supports persons with developmental disabilities.

**Visit:** [www.arcutah.org](http://www.arcutah.org)

**Benefits Outreach Program, 866-448-3616**

Service of the National Council on Aging that provides specific information to individuals about benefits they might be eligible for, as well as resources for the cost of prescription drugs.

**Visit:** [www.benefitscheckup.org](http://www.benefitscheckup.org)

**Eldercare Locator, 800-677-1116**

Helps older adults and their caregivers identify local support resources.

**Visit:** [www.eldercare.gov](http://www.eldercare.gov)

**End-of-Life Care Partnership, 888-918-4490**

Provides education and resources on preparation for end of life including the publication Toolkit for Health Care Advance Planning.

**Visit:** [www.carefordying.org](http://www.carefordying.org)

**Health Insurance Information Program (HIIP)  
800-541-7735**

Provides assistance with questions on health insurance: Medicare, Medigap, long-term care insurance.

**Visit:** [www.hsdaas.utah.gov/hip\\_contact\\_list.html](http://www.hsdaas.utah.gov/hip_contact_list.html)

**Information and Referral Center, 211 or  
800-472-4716**

Provides human service resource information and referral over the telephone, much like 411.

**Visit:** [www.informationandreferral.org](http://www.informationandreferral.org)

**Lawyer Referral Service of the Utah State Bar  
801-531-9077 or 1-800-698-9077**

Provides names of private lawyers who handle cases for a fee.

**Visit:** [www.utahbar.org](http://www.utahbar.org)

**Medicaid Fraud, 800-244-4636**

Protects the integrity of the Medicaid Program, and the safety and property of institutionalized citizens of the state of Utah, through skilled detection, pro-active investigation, prosecution, and financial recovery.

**Visit:** [www.medicaidfraud.utah.gov](http://www.medicaidfraud.utah.gov)

**Nursing Home and Home Health Care  
Quality Initiative,  
866-708-1944, ext.625**

Provides detailed information on past performance of every Medicare and Medicaid certified nursing home and home health agency in the state.

**Visit:** [www.medicare.gov/NHCompare/home.asp](http://www.medicare.gov/NHCompare/home.asp)

**RxConnect Utah, 866-221-0265**

Links you with resources to get the prescriptions you need. You must qualify for services.

**Visit:** [www.health.utah.gov/rxconnectutah](http://www.health.utah.gov/rxconnectutah)

**Social Security Administration, 800-772-1213**

Handles applications for retirement, disability, survivor's Medicare and Supplemental Security Income (SSI)

**Visit:** [www.socialsecurity.gov](http://www.socialsecurity.gov)

**Utah Coalition for Caregiver Support,  
801-538-3910**

Provides leadership and advocacy in addressing issues that impact older Utahns and their caregivers regarding information, support and access to resources.

**Visit:** [www.hsdaas.utah.gov](http://www.hsdaas.utah.gov)

**Utah Division of Aging and Adult Services  
801-538-3910**

Provides leadership and advocacy in addressing issues that impact older Utahns.

**Visit:** [www.hsdaas.utah.gov](http://www.hsdaas.utah.gov)

**Utah Legal Services, Inc.  
801-328-8891 or 800-662-4245  
(In-state toll free)**

Free legal services for low-income persons and persons 60 years of age and older.

**Visit:** [www.uls.state.ut.us](http://www.uls.state.ut.us)



**Activities of Daily Living (ADL)** - routine activities that we all do on a daily basis – bathe, dress, eat, use the toilet, move around the house.

**Advanced Directives (Advance Care Planning)** - documents that outline your wishes regarding healthcare at the end of life or in the event of a catastrophic illness. In Utah, these documents can include a Living Will, Medical Treatment Plan and HealthcarePower of Attorney.

**Assisted Living Facilities** - facilities that provide housing and assistance with ADLs, but do not provide 24-hour skilled nursing care. The level of assistance varies among facilities and may include help with bathing, dressing, meals, social activities and housekeeping.

**Case Management** - a service offered by many organizations to help coordinate community services for persons living at home, in assisted living facilities or in a nursing home.

**Co-payment** - a shared cost that a person must pay when accessing their health benefit plan (health insurance.)

**Durable Power of Attorney for Finances** - a legal document that establishes who will have legal authority to make financial/legal decisions on behalf of the care receiver and remains effective if the care receiver becomes incapacitated.

**Family Caregiver** - an adult family member, or another individual, which provides informal in-home and community care to an older individual.

**Geriatrician** - a medical doctor who specializes in the treatment of older people.

**Guardian** - an individual or organization appointed by the court to make some or most decisions about personal affairs of an incapacitated person.

**Home Health Care** - care that is received in the home or assisted living setting. It may be paid for by Medicare, insurance, or private funds.

**Hospice** - specialized care and support for terminally ill persons and their families.

**Instrumental Activities of Daily Living (IADL)** – common activities that require higher physical and mental skills – housework, preparing meals, managing our finances, getting to appointments, taking medications, etc.

**Long-term Care** - a broad range of services needed by persons with physical or mental impairments who do not have the ability to function independently.

**Personal Care** - assistance with bathing, dressing, toileting.

**Power of Attorney for Medical** – a legal document that establishes who will have legal authority to make medical decisions on behalf of the care receiver.

**Support Group** - formal or informal groups that meet to discuss issues of common interest/concern, such as caring for a person with Alzheimer’s disease, stroke or diabetes.



## Lessons in Caregiving: *Coming home from a health care facility*

Discharge from a health care facility can be a tense transition time, as a staff of professional nurses have been doing the necessary nursing tasks, and now it is up to you! Thoughtful preparation is the key to reducing caregiver stress. The following checklist covers things everyone must consider, however if your family member has more extensive needs, we encourage you to speak to the doctor in charge of your family member's care in the health care facility and the discharge planner, or social work staff:

### From the doctor:

- ☐ Do you understand the doctor's orders?
- ☐ Have you discussed the signs and symptoms in any worsening in the patient's condition?
- ☐ Are you able to read the medication labels?
- ☐ Do you understand when to give specific medications?
- ☐ Do you have emergency phone numbers available?

### Special medical equipment in the home:

- ☐ Do you need a hospital bed in the home?
- ☐ Does the patient need home oxygen?
- ☐ Do you need special equipment: pulleys, trapeze bar, raised toilet seat, etc?
- ☐ Will you need a shower chair, a removal showerhead, grab bars?
- ☐ Will the patient need special food or feeding equipment?

### Services in the home:

- ☐ Has the doctor ordered any home health nursing or therapies? (If yes, get the name and telephone number of the home health agency **before you leave the hospital**)
- ☐ Do you know what's available in the community to assist you i.e., home health aides, nurses, respite care, meals on wheels, home delivery pharmacy?
- ☐ Have you enlisted a commitment for assistance from your family, and possibly, neighbors?

### Special Considerations:

- ☐ Can you give an injection if necessary?
- ☐ Have you considered what you may have to do if your family member now uses adult diapers and is no longer able to toilet himself or herself?
- ☐ Will you need to transfer your family member from bed to a chair, or chair to toilet? Do you need training to do this safely for yourself as well as the patient?
- ☐ If your care receiver can no longer bathe herself/himself, are you able to do it for her/him?
- ☐ Your family member will need to be transported to and from doctor appointments, etc.
- ☐ Is your car too high or too low for your family member to get in and out?
- ☐ Can a wheelchair fit into the back seat or the trunk?
- ☐ Does your home need to be modified to accommodate your care receiver for example is there now a need for ramps, grab bars, etc?
- ☐ What services are covered by medical/long-term care insurance?

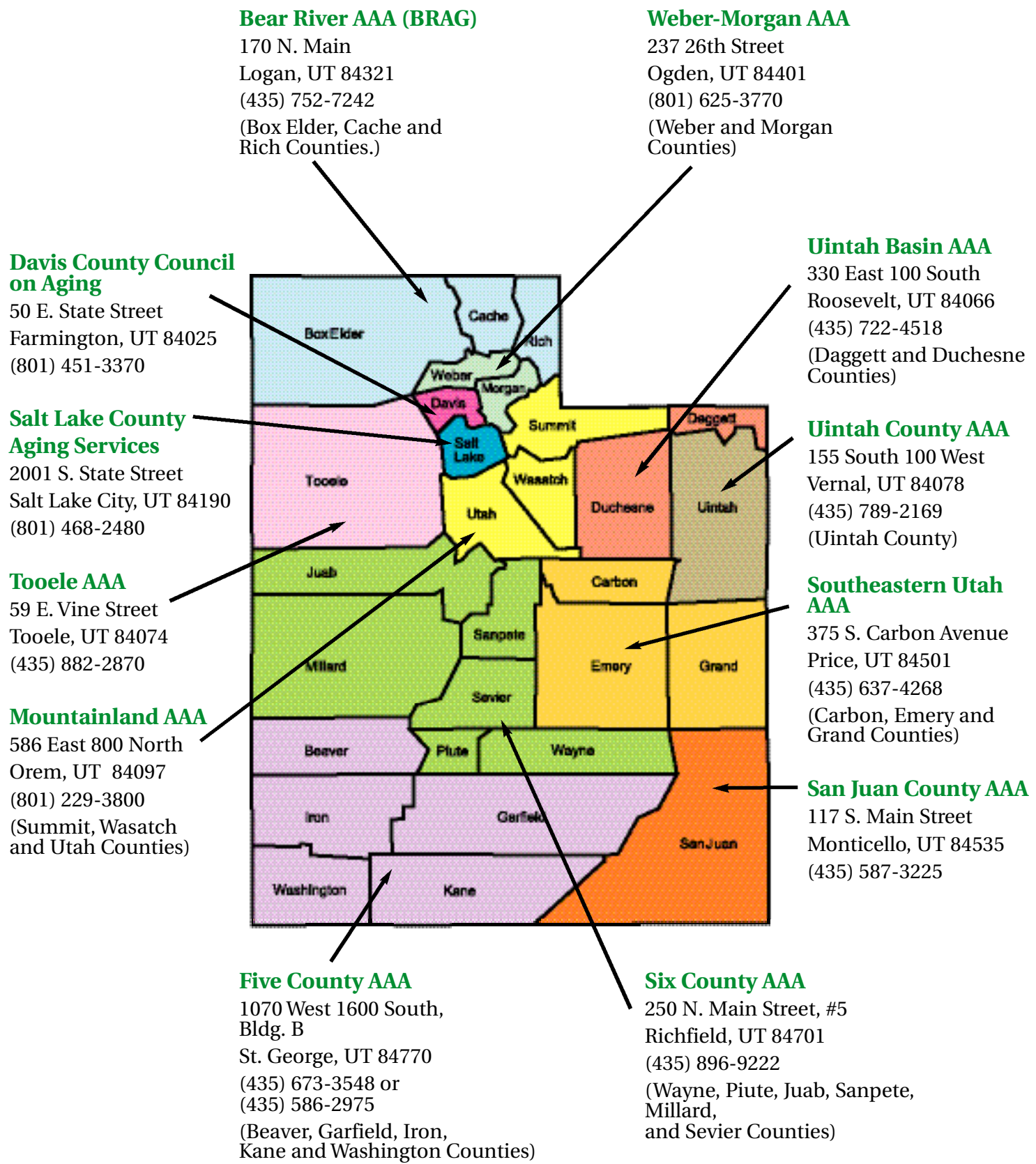
**Caregiving can be a rewarding experience. Along with the rewards come challenges. There will likely be changes in the demands on your time and energy. It is likely there will need to be some changes made in your and your family's personal life.**

**It's OK to ask for help. The Utah Coalition for Caregiver Support is committed to helping you. Contact your local Area Agency on Aging and visit our website at [www.cargivers.utah.gov](http://www.cargivers.utah.gov) or [AARP.org/ut](http://AARP.org/ut).**





## Area Agencies on Aging, by County



This publication is a result of the collaboration of members and affiliates of the Utah Coalition for Caregiver Support, the Utah Division of Aging and Adult Services, Utah Caregiver Support Program, AARP Utah and the following community partners:

American Association of University Women  
Alzheimer's Association  
CHRISTUS St. Joseph Villa  
Church of Jesus Christ of Latter Day Saints  
Golden Years Consultants  
Governor's Initiative on Families Today  
IHC Employee Assistance Program  
Jewish Family Services  
KUED Channel 7  
Legislative Coalition for Persons with Disabilities  
Rocky Mountain Home Care – Faith in Action  
Social Security Administration  
Society for Human Resources Management  
Sunshine Terrace Foundation  
University of Utah College of Nursing  
University of Utah Gerontology Center  
Utah Adult Day Services Association  
Utah Association for Home Care  
Utah Association of Area Agencies on Aging  
Utah Hospice Organization  
Utah Home Care Association  
Valley Mental Health, Masters Program  
W.D. Goodwill Social Work Initiatives on Aging, University of Utah

The Utah Coalition for Caregiver Support (UCCS) was established in March 2002. It has grown to include 32 member organizations from around the state. This diverse group meets monthly to discuss an issue they all share – *caregiving*.

To find out more about the Coalition, please visit [www.caregivers.utah.gov](http://www.caregivers.utah.gov)

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